In the Public Eye

Beyond Our Borders

Psychosocial support for breast cancer survivors

Supporting women in Ukraine

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Breast cancer is the leading cause of death from cancer among women in Ukraine. In 1998, approximately 14,600 new cases were identified and nearly 8,000 women died. Because of the severe economic conditions currently gripping post-Soviet Ukraine, medical providers face great challenges in providing basic health care, to say nothing of early detection services and optimal clinical care for women with breast cancer. In addition to the physical toll that the disease takes, the psychological and emotional needs of breast cancer patients are great but rarely are recognized formally.

Breast cancer survivors can help medical practitioners meet the psychological needs of women with breast cancer

In 1997, the US Agency for International Development supported a 3-year Breast Cancer Assistance Project to improve breast cancer services for screening, diagnosis, treatment, and rehabilitation in Ukraine.[1] Managed by the Program for Appropriate Technology in Health (PATH), a goal of the program was to enhance the cost-effectiveness of services within the constraints of existing facilities and resources. A pilot program comparing mammography with clinical breast examination showed that screening mammography is neither cost effective nor sustainable with Ukraine's current resources. For now, Ukraine must rely on clinical breast examinations to promote early detection. Through the Project, health professionals learned about clinical advances in breast cancer treatment, received training in mammography, needle biopsy techniques, and clinical breast examination. Ukrainians trained in breast examination have subsequently trained more than 1,500 health care workers.

In addition to addressing these issues in diagnosis and treatment, the Project also focused on psychosocial support for breast cancer patients.[2]

PSYCHOSOCIAL SUPPORT

Provider-patient relations

PATH conducted focus group discussions with women who had experienced breast cancer and those who had not. In addition, PATH conducted surveys of health care provider attitudes and practices related to patient care. Women reported that they often are not told they have cancer even when they have to undergo mastectomy. Instead, Ukrainian physicians usually inform other family members of the cancer diagnosis. Although some health professionals expressed support for more candor in discussions with patients, the cultural norm and official policy did not support revealing the cancer diagnosis to the patient, the concern being that such frankness would dash the patient's hope for survival.

Many women with breast cancer were dissatisfied with treatment, feeling that they received false hope and inaccurate information from their physicians. Most women wanted to know more about the disease so that they could plan the future with their families. They wanted to learn how the disease would affect their lives, what the treatment regimens and their choices were regarding treatment, and how they might combat the disease through exercise and better nutrition.

Women with a lesion or symptoms of breast cancer typically had to rely on the verbal advice of their physician for every aspect of care. Few, if any, supplemental patient education materials were available to prepare patients for upcoming events in the course of diagnosis and treatment, to explain their symptoms, or to address their concerns. In response to these findings, PATH developed print materials informing women about the disease.[3]

Bringing women together for mutual support

For many women with breast cancer, support groups can ameliorate their experience and assure them that their emotions and reactions are typical and manageable. A key goal, therefore, was to nurture existing efforts and create new opportunities for women to come together for mutual support. Although a self-help model formed the basis for the groups, several professional psychologists provided guidance. Group leaders now play essential roles in expanding the scope of activities that the groups undertake, pushing the groups beyond primarily providing mutual support into outreach, advocacy, and activism.

Survivor groups challenge the prevailing practice of shrouding the disease in secrecy. By lending mutual support, survivors not only improve their emotional and psychological well-being, but also aid their overall recovery, gaining confidence and courage to speak openly about their feelings, fears, and wishes. As women in Ukraine become more willing to publicly acknowledge their fight with the disease, they, too, can play increasingly important roles in public education.

Development of the peer-support volunteer model

As the groups matured and individual members grew stronger emotionally and physically, many women were ready to reach out to newly diagnosed women or others who were isolated or otherwise in need of support. Many women expressed the need for specific training in communication and counseling to better prepare them for this work. As a result, a peer-support volunteer program was established whereby survivors visit oncology wards to provide information and emotional support to newly diagnosed women undergoing treatment.

This program has helped to address the immediate psychosocial concerns of women with newly diagnosed cancer. It also has informed these women about community-based support groups, which many join once they have been discharged from the hospital. The volunteers do not seek to challenge the authority of doctors, but rather strive to assist them in their efforts to provide the best care possible to women. The program is completely volunteer-based and so is cost effective. The only requirements are that medical personnel trust the intentions and abilities of survivors to meet with patients and that they open their doors to those volunteers who want to help. The potential for mutual assistance between medical providers and breast cancer survivors is great, especially given the constrained economic environment in which most Ukrainian medical providers work.

SOLIDIFYING ORGANIZATIONS

Although most of the survivor groups started out informally, several have taken steps to register officially as private voluntary organizations. In addition, many have gone on to establish hotlines, organize poetry readings and art shows, seek local sponsors, and perhaps most impressive, work toward establishing a national federation of survivor groups. In May 2000, an international conference for breast cancer survivors was convened in Kiev, the first to be held in Ukraine. Survivors from Ukraine, Poland, Russia, and the United States and the professionals dedicated to supporting them exchanged information on topics ranging from self-care to advocacy and organizational development. A subsequent conference of survivors convened in April 2001, and the groups organized the first "March for Life and Hope" in Kiev in October 2001.

CONCLUSION

When PATH first discussed the idea of psychosocial support for breast cancer survivors, it was met with official skepticism but a profound expression of need on the part of individual women. Now, 15 groups represent 11 *oblasts* (provinces), with 10 of these groups officially registered as nongovernmental organizations.

In Ukraine, where current economic circumstances are extremely difficult, breast can-

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Breast cancer survivors in Kiev provide psychological support to women undergoing treatment for the disease

cer survivors have started to play a valuable role in complementing the efforts of medical providers to meet the psychological needs of breast cancer patients and their need for more information. By being willing to go public about their illness, breast cancer survivors are challenging long-held societal views about cancer and shattering the stigma that surrounds the disease. These survivors are effective role models for newly diagnosed women, serving as living proof that they not only survived breast cancer but also have gone on to live normal, productive lives.

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Creativity and chronic disease
Ludwig van Beethoven (1770-1827)

Beethoven began to lose his hearing at age 28. By age 44, his hearing loss was complete, most likely caused by compression of the eighth cranial nerve associated with Paget's disease of bone. Beethoven's head became large, and he had a prominent forehead, a large jaw, and a protruding chin (see picture)—features that are consistent with Paget's disease. Eventually, his hat and shoes did not fit because of bone enlargement.

In the movie "Immortal Beloved," based on the life of Beethoven, suggested causes of the musician's hearing loss included neurosyphilis and brain trauma related to frequent falls or other physical abuse by his father. Otosclerosis was also suspected. These three theories were discounted, however, by an autopsy performed in Vienna on March 27, 1827 by Karl Rokitansky, the father of modern morbid anatomy. Beethoven's post mortem was the first of the 59,786 autopsies with which Rokitansky is credited.

Rokitansky identified a uniformly dense skull vault and thick and shriveled auditory nerves, consistent with Paget's disease of bone. Further investigation showed no evidence of syphilitic arteritis in the auditory arteries or of recurrent otitis media. The liver, however, was atrophic, nodular, and cirrhotic. Beethoven died of alcoholic liver disease, the result of alcohol misuse by a musician whose progressive hearing loss led to depression.

Notice the prominent forehead and large jaw with protruding chin, findings consistent with Paget's disease of bone. Reprinted from Wolf PL: Clinical biochemistry and the diseases of classical music composers. *Eur J Lab Med* 1997;5:47-57.

Hearing was the sense Beethoven required more than any other. His love of music was a powerful force, preventing him from committing suicide. Much of his great music flowed from the mind of a man who never heard its beauty. He used an ear trumpet that he secured with a headband, leaving his hands free for conducting.

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